



Review article

How Marginalized Young People Access, Engage With, and Navigate Health-Care Systems in the Digital Age: Systematic Review



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 A B S T R A C T

Purpose: This systematic review examines how marginalized young people access and engage with health services and navigate health-care systems in high-income countries.

Methods: Medline, CINAHL, PsychInfo, The University of Sydney Library database, and Google Scholar were searched to identify qualitative and quantitative original research, published from 2006 to 2017, that focused on selected definitions of marginalized young people (12 to 24 years), their parents/carers, and/or health professionals working with these populations. A thematic synthesis was undertaken identifying themes across and between groups on barriers and/or facilitators to access, engagement, and/or navigation of health-care systems.

Results: Of 1,796 articles identified, 68 studies in the final selection focused on marginalized young people who were homeless (n = 20), living in rural areas (n = 14), of refugee background (n = 11), gender and/or sexuality diverse (n = 11), indigenous (n = 4), low income (n = 4), young offenders (n = 2), or living with a disability (n = 2). Studies were from the United States, Australia, Canada, United Kingdom, New Zealand, and Portugal, including 44 qualitative, 16 quantitative, and 8 mixed-method study types. Sample sizes ranged from 3 to 1,388. Eight themes were identified relating to ability to recognize and understand health issues; service knowledge and attitudes toward help seeking; structural barriers; professionals' knowledge, skills, attitudes; service environments and structures; ability to navigate the health system; youth participation; and technology opportunities.

Conclusions: Marginalized young people experience barriers in addition to those common to all young people. Future studies should consider the role of technology in access, engagement, and health system navigation, and the impact of intersectionality between marginalized groups.

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 IMPLICATIONS AND
 CONTRIBUTION

Marginalized young people experience barriers in addition to those common to all young people. Future research should explore the impact of intersecting multiple disadvantages, as well as the potential of technologies to better support marginalized young people's access to and engagement with health services and health system navigation.

Conflicts of Interest: The authors have no conflicts of interest to disclose.

Clinical trials registry site and number: This review is registered with PROSPERO no. CRD42017058602.

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In globalized societies where current generations of young people (12–24 years) are digital natives, there remain disparities in health and well-being among those who are socially and economically marginalized. Marginalized young people—those who are socially excluded—can experience multiple forms of disadvantage on the basis of sociocultural and sociodemographic backgrounds [1].

Although there are many ways to achieve equity in health outcomes across youth populations, access to timely, affordable, and appropriate health care is a major social determinant of health. These concepts of equity and the right to health have been articulated by the World Health Organization: universal health coverage means that all individuals and communities receive the health services they need without suffering financial hardship [2].

Access, engagement, and navigation around health systems are key components of universal health coverage among young people. Barriers and enablers are well known and include structural barriers (such as financial and legal barriers and cultural and community attitudes) and barriers associated with adolescence (confidentiality concerns, embarrassment, shame, and fear of being judged) [1,3]. Young people's engagement with health services has been conceptualized as reflecting a combination of knowledge about accessing health services and confidence to advocate for oneself, to communicate effectively, and the ability to follow through on plans made with providers [3]. Health professionals' perceived attitudes, communication, and involvement in care influence young people's engagement [4], especially given young people's desire for self-management [5]. The third component, health system navigation, has mostly been researched among chronically ill young people transitioning from pediatric to adult health-care systems [6,7]. These studies have highlighted the importance of preparation by pediatric services, active follow-up by adult services, and effective communication between all providers [1].

A systematic review of access and engagement with mental health care among marginalized young people found that they had heightened and distinct needs [8], as did a narrative review of research exploring homeless young people's experiences of primary health care [9]. Access barriers included confidentiality concerns, a lack of service knowledge, limited treatment options, cost, opening hours, location, waiting times, and stigma and shame associated with help-seeking. Engagement factors included negative past experiences, a lack of trust, and negative staff attitudes. Less is known about marginalized young people's health system navigation.

The digital age has created a need to examine the role of technology in access, engagement, and navigation, including the delivery of clinical care online. A systematic review examining the effectiveness of online mental health services in facilitating help-seeking has been inconclusive [10], as well as a review considering the effectiveness of social media as a health intervention [11]. However, other recent systematic reviews have indicated that technology solutions are feasible and acceptable for improving preventive behavior [12] and medication coherence in adolescents [13].

This review will determine what is known about marginalized young people's access to, engagement with, and navigation of the health system in the digital age. Our review adds to current understandings of marginalized young people's experiences of health care across settings to consider their navigation of the health system as a whole.

Methods

Review of the relevant literature

The review followed the PRISMA guidelines [14] and was registered with PROSPERO (registration number: CRD42017058602).

Table 1
Eligibility criteria

<p>Studies were included in the review if they met the following criteria:</p> <ol style="list-style-type: none"> 1. Focused on marginalized groups: refugee and vulnerable migrants; homeless; sexuality and gender diverse; living in rural and remote geographical areas; indigenous/Aboriginal and otherwise at risk (including young offenders, low income, and disability) 2. Seventy-five percent of study participants were young adults or adolescents (age range 12–24 years), their parents, or health professionals (key informants). 3. Reported on barriers and/or facilitators to access, engagement and/or navigation of health-care systems 4. Were from developed high-income countries 5. Reported original research 6. Published from 2006 onward

A literature search was performed using Medline, CINAHL, PsychInfo, The University of Sydney Library database, and Google Scholar. The reference lists of review articles identified in the search were hand searched and screened for inclusion in the current review. Articles were restricted to those published between January 1, 2006, and February 26, 2017, to capture research conducted in the digital age. We define the "digital age" as the era when the use and availability of technologies rapidly expanded, for example, via the availability of smartphones and other portable devices, and the advent of social media. Database searches were not limited by language or full text. The search strategy was planned in consultation with a librarian from The University of Sydney.

The search involved two phases. The first combined thesaurus terms relating to health-care access, barriers, or navigation with keywords synonymous with young people. We defined marginalized young people in sociocultural and sociodemographic terms, rather than by illness or disability. To gain a broad understanding of the experiences of these populations, we conducted the second phase of our search with keywords representing five specific marginalized groups (homeless young people, rural, refugee and vulnerable migrants, gender and sexuality diverse, and indigenous) and keywords relating to health care. Subsequently, as we reviewed the literature, we identified other groups that were relevant to our broad research question search (low income, young offenders, and disability), so these were also included; however, a systematic search of the databases was not conducted using these terms. Appendix S1 provides a description of search terms. Studies were included if they met the criteria listed in Table 1.

Study selection

Abstracts of the initial database searches were screened. Inter-rater agreement was assessed by two researchers independently screening 200 articles, achieving agreement of more than 95%. Consensus was reached via discussion where abstracts received discrepant ratings.

Data extraction

We extracted study characteristics and outcomes and entered these as data into an Excel database (Microsoft Corp., Redmond, WA). Data extracted included year and language of publication, country, marginalized group, study design, sample size (of young people, parents, and professionals), age definition (of youth participants), gender distribution (% female and % transgender or

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